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The Role for Community-Based Participatory Research in Formulating Policy Initiatives: Promoting Safety and Health for In-Home Care Workers and Their Consumers

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Although community-based participatory research (CBPR) can be effective in influencing policy, the process of formulating policy initiatives through CBPR is understudied. We describe a case study to illustrate how alliances among various community partners could be united to formulate policy directions.

In collaboration with partners, the National Institute for Occupational Safety and Health initiated a project aimed at improving health and safety for low-income elderly and disabled persons and their in-home care workers. Community partners and stakeholders participated in focus groups, stakeholder interviews, and meetings; they played multiple roles including identifying organizational policy changes the partners could initiate immediately, as well as broader public policy goals.

Results indicated that a strong community partnership, participation, and shared values contributed to successful formulation of policy initiatives. (*Am J Public Health.* 2009;99:S531–S538. doi:10.2105/AJPH.2008.152405)

COMMUNITY-BASED PARTICI-patory research (CBPR) has gained support as an effective approach to addressing environmental justice issues.[1–3] It emphasizes community involvement in applying scientific knowledge to reduce adverse health outcomes, sometimes through changes in health policy. To date, the process of developing and implementing policy change through CBPR is understudied.[4] An evaluation of policy initiatives in four environmental justice projects underscored the importance of strong community leadership, participation, organizational skills, and shared values among partners.[1] Themba and Minkler proposed a multistage process for implementing policy change through CBPR beginning with careful formulation of policy directions. When community partnerships identify and refine common policy objectives, advocating those strategies may be more successful.[3]

We describe a case study of the policy formulation process in a unique intervention project targeting the intersection of the home and work environment for two economically marginalized populations—low-income elderly and disabled persons and the low-wage in-home care workers who help them live independently. The on-going study, Partnership for Safety: Making Homecare Safe for All, aims to identify health risks and develop intervention programs to improve health and safety through partnerships between in-home care workers and their clients (consumers) in Alameda County, California. This project demonstrates how alliances among various (and sometimes conflicting) partners within the community could be used to formulate policy directions to improve this challenging home or work environment.

BACKGROUND

Currently 1.5 million in-home care workers in the United States

serve 7.6 million elderly or disabled persons, with 16 000 working in Alameda County.[5,6] With main responsibilities of providing personal care as well as housekeeping, meal preparation, and shopping, in-home care workers are mostly women (88%) who are racially and ethnically diverse.[7,8] In Alameda County, 43% of in-home care workers are African American, 25% are Asian, and 7% are Hispanic.[9] It is one of the fastest growing occupations, projected to increase by 50% in the next 10 years.[6]

The history of the in-home care industry nationwide and the unique alliance of advocates for worker and disabled- and elderly-person rights in California provide a context for the project's partnership. Nationally, several concurrent movements in the 1960s converged to create the modern in-home care industry: the Older Americans Act (1965) generated state programs promoting greater independence for elderly persons, public welfare amendments encouraged job training for welfare recipients, and Medicaid and Medicare provided funds to pay for in-home care services.[10]

California became a policy leader in promoting an active independent living movement and developing in-home care services to serve its large elderly population. In 1973, In-Home Supportive Services (IHSS) was created as a statewide entitlement program administered by the counties providing in-home care services to low-income elderly and disabled persons. Independent living advocates convinced legislators to adopt a consumer-directed model, giving clients control over workers' hiring and firing, while the state continued to pay their wages.[10]

The program rapidly expanded, yet the challenges of retaining a qualified workforce because of low wages and a lack of benefits threatened its sustainability, leading some legislators to support greater use of contract in-home care agencies to ensure better provider quality.[10,11] Disability rights activists, especially the independent living movement, strongly opposed this solution, viewing the agency model as disempowering, and built an unusual alliance with labor unions interested in organizing in-home care workers.[12] This alliance crafted a historic policy agenda giving unions the right to advocate for improved wages and benefits while maintaining consumer direction. In 1992, legislation created county-level public authorities to act as employers for negotiating wages and benefits and gave consumers a policy-level voice in IHSS, including the consumer's right to hire, direct, and terminate a in-home care worker.[10,12]

Since 2000, although at least 27 states have incorporated consumer direction as one component of their in-home care services,[13] many have identified responsibility for the protection of in-home care workers' safety and health as an important gap.[14,15] As employers, the elderly and disabled lack easy access to information and resources to protect worker safety; the state, because it is not the employer, has no legal responsibility.[16] Inadequate training and safety protections in the home and work environment present risks for both workers and consumers.[17,18]

Recognizing this gap, in 2001 community partners (the labor union and the Alameda County Public Authority for IHSS [hereafter "Public Authority"]) in Alameda County jointly requested that the National Institute for Occupational Safety and Health evaluate safety within their in-home care program. The ensuing study demonstrated many hazards, but also heard resistance by independent living advocates to traditional standards-based approaches to protecting worker safety that might compromise consumers' control over their home environment.[19] The Partnership for Safety project emerged as one solution and provides a case study of how involvement of community partners and stakeholders led to a collective understanding of the benefits of home and workplace safety. Stakeholders included service providers and advocacy groups for consumers such as the Center for Independent Living and World Institute for Disabilities, advocacy groups for in-home care workers such as Family Caregiver Alliance and *Mujeres Unidas* (Women United), and in-home care workers and consumers.

METHODS

The Partnership for Safety has multiple goals, which include (1) raising awareness of occupational health and safety issues, (2) developing and evaluating educational materials to aid in the promotion of worker and consumer safety, (3) increasing the extent to which occupational safety and health issues are considered when policy decisions relevant to in-home care are made, and (4) identifying and advocating policy changes that are likely to enhance worker and consumer safety. The term "policy" is relatively broad, but typically refers to a course of action or overall plan intended to guide present and future decisions. In occupational health, both public policies (such as legislated regulations) and organizational or human resource policies and practices (such as how workloads are determined and whether appropriate resources and training are provided) are important contributors to the promotion of worker health and safety.[20]

We focused on how the CBPR process can aid in the identification of both types of policy initiatives, as well as the identification of smaller programmatic changes that stakeholders could implement as small steps toward larger policy changes. In phase I of the project (2006–2008), the project team researched and developed intervention materials, and in phases II and III (2008–2010), the team is field testing and evaluating the intervention. Throughout phase I, community partners and stakeholders played multiple roles including identifying barriers, facilitating development of intervention materials, and formulating policy.

Community Partners and Stakeholders

The project has four partners: the Public Authority and its advisory board containing a majority of consumers; the Service Employees International Union United Long-Term Care Workers Union, representing the workers; the Labor Occupational Health Program at the University of California (UC), Berkeley; and the

National Institute for Occupational Safety and Health. All four partners are involved in all stages of the project, including writing the funding proposal, developing focus group and key informant interview scripts and recruiting participants, and contributing content, choosing designers, and reviewing drafts of intervention materials.

The iterative and collaborative process can be illustrated by the example of focus group and interview script development. All partners brainstormed ideas together. Then the research partners (from UC Berkeley and the National Institute for Occupational Safety and Health) summarized the proposed ideas, reviewed existing literature on focus group and interview methods, and completed the initial drafts of the scripts. Community partners reviewed the drafts, offered feedback, and actively recruited the participants. At the initial phase of the project, the partners collaboratively established a stakeholder committee.

Conceptual Framework for Policy Change

Conceptual frameworks for policy advocacy can be useful tools to guide policy change.[3,21] For example, Ritas proposed a framework starting with identifying community issues, to assessing the political environment, developing strategies, and finally, taking action.[21] This framework identifies a hierarchy of levels of policy change ranging from governmental institutions to oversight bodies and organizational-level policies and practice. The project team adapted this framework, especially recognizing the importance of identifying internal organizational policies and practices that project partners could implement. Because one of the main concerns of the project was to raise awareness about worker safety and health at the community level, partners felt that initiating changes at the community or organizational level would facilitate building broader support and advocacy for more-ambitious regulatory and funding changes at the state and county level. These regulatory and funding changes would then sustain and promote new community initiatives and ongoing advocacy for safety and health (Figure 1).

Research and Stakeholder Activities

The project team conducted a series of research activities with the purpose of encouraging community members and key stakeholders to voice concerns and address barriers to improving health and safety. Six focus groups were conducted with in-home care workers and four with consumers in English, Spanish, and Cantonese. Each focus group lasted 2 to 3 hours. Participants were recruited through the project's community partners and received $40 grocery vouchers. Two annual stakeholder meetings were convened in 2006 (with 25 stakeholders) and 2007 (with 21 stakeholders). Ten follow-up key informant interviews were conducted with stakeholders. One additional focus group included IHSS social worker supervisors.

All focus group and interview data were audio-recorded and transcribed. The transcripts were imported to NVivo 7.0 (QSR International Inc, Cambridge, MA), a qualitative data-analysis software program. All partners had access to the transcripts; however, the research team conducted initial coding, guided by a modified grounded theory.[22] Codes emerged inductively, with two researchers analyzing the transcripts independently, paying particular attention to institutional barriers to health and safety in the current IHSS system and proposed suggestions to improve the overall program. Two researchers compared, discussed, and consolidated their codes and then gathered feedback from other project partners. Stakeholder meeting summaries were also compared with the analyses to produce the final report.

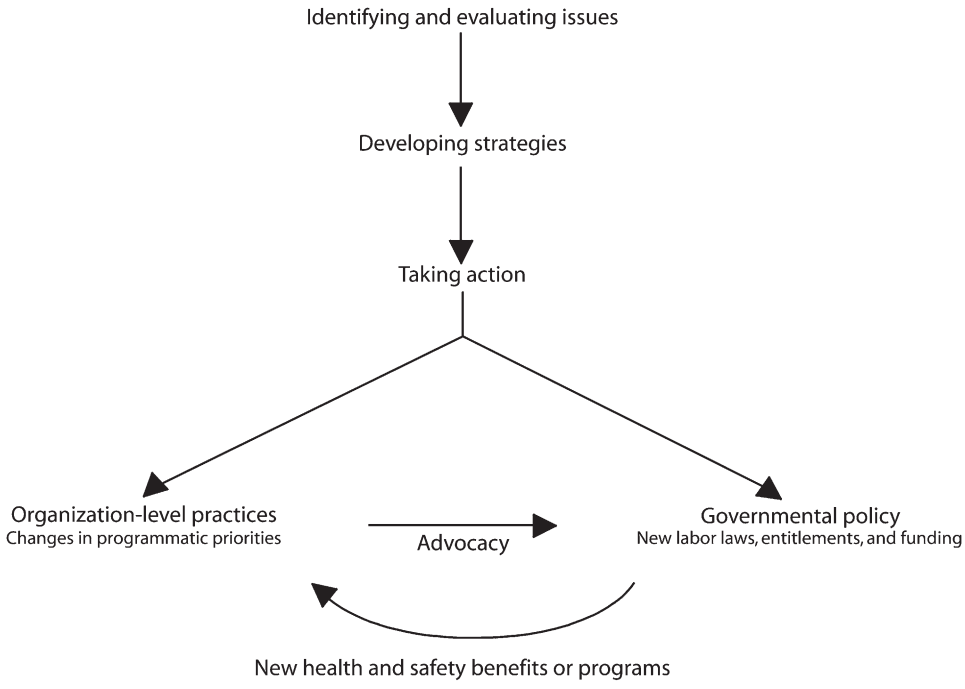

FIGURE 1—Conceptual framework for policy change.

Formative Evaluation of Partnership Capacity

Because of the conceptual support and empirical evidence for the importance of partnership capacity to the success of CBPR policy efforts,[1,23,24] an external consultant worked with the partners to identify strengths and challenges through semistructured qualitative interviews after the first year of the project. The external consultant was chosen for her expertise in evaluating CBPR projects and in occupational health and safety. All four partners assisted the consultant with developing the protocol, and representatives participated in confidential hour-long interviews addressing group dynamics and perceived strengths and weaknesses of the partnership. The interviews were audio-recorded, transcribed, and analyzed to discern common themes and unique perspectives among the partners.

RESULTS

Table 1 summarizes institutional or organizational barriers to safety and health identified by community members and stakeholders and the sources (focus groups, key-informant interviews, and stakeholder meetings). We prioritized problems identified by multiple sources that would likely have broader community support.

Community Input Into Policy Formulation

Inadequate worker capacity and accountability. A major issue raised by all was the need to increase worker capacity and accountability by increasing training and formalizing the roles and responsibilities of both the consumer and worker. For example:

> It's just so important that the consumer can expect a professional to come into their home and do this work and be responsible and get things done. (Stakeholder interview R1, representing consumers' perspective)

> [I]f it were a little more formal I think more people would feel like it's okay to have some person that I don't know coming into my home because it's a job and I'm hiring them and I have certain responsibilities to them and they have certain responsibilities towards me. (Stakeholder interview R4, representing worker's perspective)

TABLE 1—Policy Issues Identified and Suggestions Proposed by Community Members and Stakeholders: Promoting Safety and Health for In-Home Care Workers and Their Consumers, Alameda County, CA, 2006–2008

	Cited in:				
Institutional or Policy Issues	HCW Focus Group	Consumer Focus Group	Stakeholder Interview (HCW)	Stakeholders Interview (Consumer)	Stakeholder Meetings
Worker capacity and accountability					
Most workers and consumers do not have clear guidelines and requirements of the job.	√	√	√	√	√
In-home care workers lack formal training on health and safety.			√	√	√
Consumers need to be more aware of their responsibilities as employer.				√	
Health and safety resources and equipment: consumers lack resources and equipment.	√	√	√	√	√
Liaison between in-home care workers and consumers (advocacy for worker rights)					
Workers need liaison when there are work-related problems.	√	√	√		√
Workers are not covered by Fair Labor Standards.			√		
Workers are not protected from being fired (e.g., no 2-wk notice policy).			√		
Workers are not protected from sexual harassment.			√		
Assigned hours of work: workers often are not assigned enough time to do the job safely.	√			√	√
Roles of social workers: social workers are inaccessible to in-home care workers.	√				√
Referral system or registry list					
The referral system is ineffective.	√		√	√	√
There is inadequate information on in-home care workers in the system.					
Fringe benefits of in-home care workers					
Workers do not have sick or vacation leave, paid time off, or overtime pay.	√		√		
Workers do not have travel pay.			√		
Workers may not get paid when consumer is in hospital.			√		
Workers sometimes have problems with their health insurance.	√				

Note. HCW = in-home care worker.

Lack of worker capacity and accountability was specifically tied to safety and health through three main pathways: (1) unclear guidelines for job tasks and job requirement, (2) inadequate training for in-home care workers on performing their job safely, and (3) lack of awareness by many consumers of their responsibilities, as employers, to protect workers. Although consumers are given a list of broadly defined "authorized tasks" and approved number of hours of services, they have broad discretion to organize the specific job tasks as they choose. For some in-home care workers, this provides a positive sense of job flexibility, whereas for others it creates role ambiguity, a well-recognized work stressor.[25]

All partners acknowledged the importance of in-home care training and felt it was inadequate, particularly concerning health and safety. Training is not a standard requirement for new in-home care workers. Some workers pay for their own training, and others (about 500 per year) take advantage of free voluntary trainings provided by the Public Authority during unpaid work hours. Some stakeholders indicated that lack of training might cause higher rates of injuries and could compromise the quality of care. They recommended documenting the magnitude of such problems.

Stakeholders felt that some consumers were reluctant to take full responsibility as employers. One talked about how increasing awareness of consumers' responsibilities may have positive effects:

> [T]he more we can make [older and] disabled people aware of their responsibility as employers, the better effect[s] on their sense of power in the society, on their sense of responsibility for the needs of their employees and the people that care for them, and that can't help but have a positive effect on their sense of self and they're taking care of their own physical and emotional needs. (Stakeholder interview R7, representing consumers' perspective)

To increase worker capacity and accountability under the consumer-directed model, stakeholders proposed a number of useful strategies: (1) a "contract" or job agreement between the consumer and worker with clear guidelines, (2) minimal or mandatory training, and (3) a career ladder in which in-home care workers with greater training could receive higher levels of pay.

Inadequate availability of resources and equipment. Consumers' lack of resources and equipment creates barriers to health and safety. Being low-income and disabled or elderly, consumers lack adequate financial and informational resources to improve the home or work environment. In focus groups, workers recounted how their consumers did not have and sometimes refused to provide equipment such as cleaning chemicals, gloves, and vacuum cleaners. One in-home care worker stated,

> The elderly lady that I'm taking care of . . . has no clue of what to do for me [and] has no resources to help me with my back or anything like that (English focus group, in-home care worker).

Stakeholders pointed out a number of existing resources. For example, every independent living center has an assistive technology specialist, and there are online databases (stakeholder interview R2, representing consumer's perspective). Stakeholders also recommended that the union and other organizations establish a lending library to provide consumers and workers with free and low-cost assistive devices and other equipment, information, and resources.

Limited advocacy for workers' rights within the IHSS program. Although the IHSS program provides payroll services, most other traditional employer-provided worker support services are nonexistent. Furthermore, in-home care workers are excluded from protection under certain labor laws governing maximum hours of work or overtime pay (stakeholder interview R8, representing workers' perspective). In reality, the complexity of in-home care workers' multiple employers (i.e., consumers, as well as the state, the county IHSS system, and the Public Authority) makes it more challenging to advocate for workers' rights. When work-related problems occur, workers expressed frustration and helplessness because they perceive there is nowhere to obtain assistance. Examples of work-related problems included fear of losing jobs, delayed pay, sexual harassment, and requests to perform tasks beyond those authorized (as ascertained from focus groups of in-home care workers).

Social workers assist consumers; however, their heavy case loads limit time with each client. Although IHSS social workers expressed support for efforts to address health and safety, they felt unable to assume any active role in advocating health and safety rights for workers or providing health and safety information if such activities impacted their workload. One commonly expressed concern was that social workers assign insufficient in-home care hours to work safely. To address these problems, stakeholders proposed an IHSS ombudsperson position be created to serve as the liaison between in-home care workers and consumers. Others suggested that if social work caseloads were reduced and their official duties were expanded, they could play an important role in identifying problems during required annual home visits, if this was included in their official duties.

Partnership capacity. The partnership members shared similar perceptions of the team's major strengths and current challenges (Table 2). The partnership has created a context or culture in which "everyone matters"; all members feel that they have a voice in decision-making and that their contributions are appreciated. Another important dimension is that "everything gets done"; partners expressed admiration for the varied skills of team members and satisfaction with the division of labor in completing important project activities. At the same time, the partners expressed some trepidation about the next phases of the project (intervention implementation) because of the challenges and the need to broaden community participation.

Partnership Policy Formulation Process

The partners used a facilitated brainstorming and consensus prioritization process to develop

internal programmatic practice and policy suggestions as well as broader public policy ideas. Recognizing the importance of building community awareness to more successfully advocate for broader public policy changes, the partnership has generated several initiatives. For example, a social marketing campaign including the use of posters and safety fairs is being developed and implemented. Project partners also created a subcommittee to refine the list of concerns and to set specific policy and practice objectives. Here we describe internal organizational practice and policy changes that the partners could initiate themselves, as well as broader public policy initiatives requiring ongoing collaboration and advocacy by partners and stakeholders.

Internal organizational practice and policy changes. Project partners proposed some practice and policy changes at the organizational level, which included:

1. Providing educational information: The Public Authority's *In-Home Supportive Services Handbook—Alameda County*[26] has been revised to include content to increase consumers' and in-home care workers' awareness of the importance of health and safety on the job. An informational kiosk that includes safety and health information has been approved for the main administrative lobby of the Alameda County IHSS, where in-home care workers come regularly to submit paperwork, including timesheets. The kiosk will include model "contracts" that consumers and workers could use when first defining worker job tasks and consumer responsibilities.
2. Improving access to resources: project partners and stakeholders are discussing the creation of a lending library to provide free and low-cost equipment, assistive devices, and other resources. Improving access to these resources would be an important step in creating ongoing support for advocating worker safety and health.
3. Building project support: both the County Board of Supervisors and IHSS have committed in writing to support the use and dissemination of the educational materials developed by the Partnership for Safety project. In addition, they have committed to supporting inclusion of the importance of considering safety in determining the time needed to perform IHSS-approved tasks within IHSS social worker orientation and training and, when workload permits, to distribute

TABLE 2—Formative Evaluation of Partnership Team Capacity: Promoting Safety and Health for Home Care Workers and Their Consumers: Alameda County, CA, 2006–2008

Common Themes	Illustrative Quotes
Strengths	
Experienced, highly skilled leaders embedded in strong autonomous partner organizations	"All of us [partners] are pretty experienced, not only in health and safety but in in-home care."
	"She is a really good diplomat and really great at what she does in terms of convening and coordinating and bringing folks together."
	"She's super respected and loved by the people she works with."
Strong interpersonal relationships characterized by trust and respect	"It is relationships that 'grease the wheels' of any project and it has helped tremendously that everybody trusts everybody else."
	"I feel totally respected for what I bring to the group. And I think everyone else does, too."
Awareness and acceptance of different priorities of partner organizations, coupled with a commitment to finding common ground	"There had been times when we had worked pretty closely with consumers. Individual consumers, or as a coalition. There have also been times when it has been hard, and we are up against each other. I thought of health and safety as an area where consumers really have the best interests of the home care workers. It improves their own safety, too."
	"Everybody agreed that some good was going to come of this anyway, even though they had reservations."
	"Everyone respects everyone else's domain."
Mutual appreciation of the complementary skills of CBPR partners	"I would say that there has been an amicable learning from each other."
Federal funding and support of initiative Challenges	"The way NIOSH can work in the long term and in leveraging those kinds of dollars . . . that's amazing.
Broadening and deepening the participation of community members	"So the next stage, where we need to identify worker leaders and have more grassroots, long-term involvement of home care workers, that's going to be more difficult."
Turnover and changes within partner organization	"Right now, maybe a barrier would be consistency. . . . You need consistency in who is involved—both the staff and the member leaders."

Note. CBPR = community-based participatory research; NIOSH = National Institute for Occupational Safety and Health.

the project's materials during their regular visits with consumers.

Public policy initiatives. Beyond these internal organizational changes, the partnership formulated and prioritized more-ambitious public policy initiatives requiring state or county support and funding. Implementing policy proposals that require new legislation or funding is challenging because California is facing a severe budget shortfall, with cuts being proposed for the Public Authorities and the IHSS program.

One partnership priority, the creation of an ombudsperson to offer advice and assistance for problems or disagreements between consumers and workers, was presented to the assistant agency director of the Alameda County Adult and Aging Services in a formal letter and meeting with the project partners. The other priority, paid training for workers and consumers, has been proposed to members of the County Board of Supervisors in stakeholder meetings by consumers on the Public Authority advisory board and by in-home care workers speaking through their union. Although the previously mentioned proposals are long-term commitments that would require county and state budgetary support, the meeting between the partners and the assistant agency director of the Alameda County Adult and Aging Services helped to outline what specific steps the partners might consider in building a campaign to achieve these objectives. For example, it was recommended that the project team clearly document the potential cost savings associated with injury and illness prevention, such as avoiding paying for emergency backup care when a worker is injured.

DISCUSSION

The Partnership for Safety project has engaged research and community partners in the process of collectively identifying barriers and formulating policy and practice initiatives to promote health and safety for both consumers and in-home care workers. Consistent with previous literature, a strong community partnership, participation, and shared values contributed to successful formulation of these initiatives.[1] The participation and input from a wide range of community members and stakeholders promoted a common belief that attention to worker safety would benefit and empower both consumers and workers.

Concrete policy changes are challenging to achieve, particularly those that require new legislation and government funding. Previous articles that have reported on the success of CBPR in addressing environmental justice issues have focused primarily on advocacy for governmental policy changes.[4] Adapting Ritas'[21] framework, this project examined a hierarchy of levels of policy change focusing also on organizational-level policy and practice changes. By demonstrating their own commitment and leadership in formulating internal programmatic practices and policies, the project partners hoped to build ongoing support and advocacy for broader public policy changes. For example, although securing funding for paid training programs is a long-term goal, a short-term, more practical goal was revising the IHSS handbook, initiating an equipment lending library, and creating kiosks with safety information. Once implemented, these changes should increase awareness and interest in advocating at county and state levels for new funding for ongoing health and safety programs.

The CBPR approach is valuable in guiding academic and community partners to identify issues and formulate policy and practice priorities.[3] Only after successful policy formulation, when community and research partners appropriately analyze problems, jointly develop strategies, actively implement organizational changes, and build support for ongoing advocacy, can broader policy impact be achieved. Whether these initiatives will be successful in increasing worker and consumer satisfaction and improving safety and health cannot yet be evaluated. The next stage of the project will focus on implementing the planned educational interventions. During this stage the project partners will need to develop strategies to influence decision makers and mobilize financial, personnel, and other resources to sustain and advance these efforts. ■

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Contributors

F. Gong participated in the study, led the writing, and initiated the topics. S. Baron was the principal investigator of the study, supervised the study, and led the writing. As community partners, L. Ayala and S. McDevitt participated in the study, helped recruit respondents, and reviewed the article. As research partners, L. Stock facilitated the focus groups, participated in the study, and reviewed the article, and C. Heaney conducted evaluation of the partnership, produced the evaluation report, and reviewed the article.

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Human Participant Protection

This study was approved by National Institute for Occupational Safety and Health's institutional review board and the University of California, Berkeley's institutional review board.

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Community Campaigns, Supply Chains, and Protecting the Health and Well-Being of Workers

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The growth of contingent work (also known as precarious employment), the informal sector, and business practices that diffuse employer responsibility for worker health and safety (such as outsourcing and the development of extended national and international contracting networks [supply chains]) pose a serious threat to occupational health and safety that disproportionately affects low-wage, ethnic minority, and immigrant workers.

Drawing on cases from the United States and Australia, we examine the role that community-based campaigns can play in meeting these challenges, including several successful campaigns that incorporate supply chain regulation. (*Am J Public Health.* 2009;99:S538–S546. doi:10.2105/AJPH.2008.149120)

THE 40 YEARS AFTER 1880 was a period of significant social reform that saw the rise of organized labor and the launch of broad community campaigns to improve living and working conditions, recognize unions, enhance the political voice of workers and women, and provide legislative protections (for example, anti-sweating leagues were established to oppose the gross exploitation of workers). This period also